

Original Article**Psychosocial and Financial Needs, Burdens and Support, and Major Concerns among Greek Families with Children with Autism Spectrum Disorder (ASD)****Vassiliki Ntre**

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Abstract

Background Families of children with autism spectrum disorders (ASD) are burdened both psychologically and financially. This study investigated the general concerns and the needs for support and information of Greek mothers of children with ASD, their health problems and the family financial burden.

Methods Study was made of 61 mothers (mean age: 43.69±5.84 years) of children with ASD (86.9% boys, mean age: 10.33±2.9 years), who completed questionnaires assessing the family environment, burden and needs regarding the child, and maternal depression and health problems. **Results** The majority of mothers (67.5%) reported depressive symptoms and health problems. Having a child with ASD put a high load on the family finances; families paid out of their own pockets amounts ranging from €401 to €1,000 per month, and in half of the families a member had to get a job or work extra hours to cover the expenses of the child's therapy. The main maternal concerns were for the child's future development 58.18%, about which they reported needing more information. The family environment was characterized as positive by 70.36%. They reported a low level of agreement between mothers and fathers on issues related to the upbringing of their child. **Conclusions:** Having a child with ASD has a substantial impact on maternal wellbeing, and finances, and family life in general. The need for support of families of children with ASD is pressing, and priority should be given to the funding, accessibility and improvement of the quality of public services for this population.

Key words: Autism spectrum disorder, children, mothers, financial burden, family needs

Introduction

Autism spectrum disorder (ASD) is a heterogeneous neurodevelopmental disorder with wide individual differences. It is characterized by persistent deficits in social communication and social interaction, restricted and repetitive patterns of behavior, interests, or activities, and possible intellectual disability, which begin in the first years of life (American Psychiatric Association, 2013). Parents raising a child with ASD face a series of challenges and daily stressors related to a wide variety of factors, including existential concerns due to the unknown etiology of ASD and lack of understanding of its nature (Dale, Jahoda, & Knott, 2006), increased child needs and parenting demands, the restricted availability and accessibility of suitable interventions, and the associated financial burden (Seltzer, Abbeduto, Krauss, Greenberg, & Swe, 2004; Schieve, Blumberg, Rice, Visser, & Boyle, 2007). A number of studies on the experiences of parents of children with ASD in developed countries have revealed multiple unresolved problems (e.g., Luong, Yoder, & Canham, 2009; Tzoy, Connolly, & Novak, 2007; Woodgate, Ateah, & Secco, 2008). Practical and financial difficulties in parenting are documented and the increased involvement in the care of the child contributes to maternal psycho-emotional exhaustion and discomfort (Firat, Diler, Avci, & Seydaoglu, 2002; Hastings et al., 2005; Schieve et al., 2007; Sivberg, 2006; Weiss 2002). Mothers of a child with ASD often abandon their personal life and their individual targets, restricting their own development and career (Järbrink, Fombonne, & Knapp, 2003; Schieve et al., 2007; Wolf, Noh, Fishman, & Speechley, 1999). It is therefore not surprising that parents who are raising a child with ASD are at risk of developing mental health problems (Piven & Palmer, 1999; Wolf & Fisman, 1989). The mothers in particular have been reported to present more physical problems than mothers of healthy children, and higher levels of stress, anxiety, uncertainty, alexithymia, anger, depression, withdrawal and isolation (Dale et al., 2006; Dunn, Burbine, Bowers, & Tantleff-Dunn, 2001; Estes et al., 2014; Firat et al., 2002; Hastings et al., 2005; Honey, Hastings, & McConachie, 2005; Schieve et al., 2007; Weiss, 2002; Wolf et al., 1999).

Regarding the impact of ASD on the family, it is documented that the presence of a child with

ASD is associated with a significant reduction in family income, but at the same time high costs are incurred, and many families face financial difficulties in covering the expense of special child health care and educational needs (Järbrink et al., 2003; Montes & Halterman, 2008). New family needs emerge, for example parents seek emotional and social support, and they search for information about ASD and the availability of public health care services (Bailey & Simeonson, 1988; Lustig, 2002; Moes, Koegel, Schreibman, & Loos, 1992; Taylor, 2007). Changes take place in family activities, with increased child supervision and a decrease in social life (Weiss, 2002), leading to greater social isolation or withdrawal (Tunali & Power, 2002; Weiss, 2002). The findings of these studies are consistent with calculations that parents of children with ASD spend, on average, an extra 1,000 hours per year on care and support of their child (Järbrink, McCrone, Fombonne, Zanden, & Knapp, 2007). These multiple child health-related commitments put huge pressure on families and prevent them from enjoying life to the full (Dale et al., 2006; Dellve, Samuelson, Tallborn, Fasth, & Hallberg, 2006; Divan, Vajaratkar, Desai, Strik-Lievers, & Patel, 2012; Dunn et al., 2001; Sivberg, 2002), and are associated with lower levels of marital happiness, family cohesion and adaptability (Higgins, Bailey, & Pearce, 2005; Sivberg, 2006). Children with autism find it difficult to participate in family and school activities, and this affects various dimensions of the quality of life of the whole family (Lee, Harrington, Louie, & Newschaffer, 2008).

Limited awareness of and access to appropriate health care services for children with ASD may intensify the impact on the economic and emotional burden of the family. Greater needs can be identified among the most isolated families, who have less social and emotional support and limited access to the evidence-based interdisciplinary services for children with ASD (Divan et al., 2012). The assessment of their needs can contribute to interventions aimed at reducing the stress that families experience in seeking care for the child (Koegel, Bimbela, & Schreibman, 1996; Krantz & McClannahan, 1998; Krantz, MacDuff, & McClannahan, 1993; Cappe, Wolff, Bobet, & Adrien, 2011). Exploration of the specific needs of families can lead to reduction of their stress and contribute to

improvements in the health and quality of life of both the children with ASD and their families.

The emotional and health impact of ASD, parental concerns for the child's future, and parental needs have been investigated in a small number of studies on Greek families (i.e. Genna, 2006; Konstantareas & Papageorgiou, 2006; Loukisas & Papoudi, 2016; Veroni, 2016). To the knowledge of the authors, there has been no study of the financial impact of ASD on Greek families.

The purpose of this study was to investigate the psychological and financial burden and the needs related to information about ASD and support and finance, among mothers of children with ASD in a Greek population.

In addition, this study aimed to explore the general health of the mothers, their concerns for the future of their children and their perceived social support, the distribution of parental responsibility for the upbringing of the child and family cooperation. Hence, our hypothesis was that having a child with ASD may have an impact on maternal wellbeing, family financial needs and family functioning

Method

Participants

All mothers of children aged 6-17 years with ASD who attended the ASD outpatient clinic of the Department of Child Psychiatry, National and Kapodistrian University of Athens, at the "Aghia Sophia" Children's Hospital were invited to participate in the study. The exclusion criterion was inability to read or write adequately in the Greek language.

Of the 66 mothers who were eligible, 61 agreed to complete the study questionnaires. The mean age of the participants was 43.69 ± 5.84 years, and that of their children with ASD 86.9% of which were boys, was 10.33 ± 2.9 years, range 6-17 years.

Study instruments

Demographic Characteristics and Financial Burden Questionnaire. This questionnaire, which was developed for current study, covers the child's gender and age, the parents' age, nationality, marital status, educational/occupational status, the number of children in the family and the siblings' health problems, and the

expenses for the child's treatment, insurance coverage and out-of-the-pocket payments).

Maternal Health Problems, Concerns and Child Difficulties Questionnaire. This questionnaire, which was developed for the current study, consists of 20 questions about parental health problems, child difficulties, family cooperation and parental concerns for the future.

Family Needs Survey (Bailey & Simeonsson, 1988). This consists of 35 items which examine the functional needs of parents with handicapped children. The questionnaire includes 6 subscales (needs for information, needs for support, explaining to others, community services, financial needs, family functioning). For the purpose of this study, 3 of the subscales were used (needs for information, needs for support and financial needs). The items are scored on a 5 point Likert scale.

Center for Epidemiologic Studies Depression Scale (CES - D; Radloff, 1977). This is a self-reported questionnaire that consists of 20 items, measuring the presence of depressive symptoms in the past week, on a 4-point scale ranging from 0 (rarely) to 3 (most of the time). A score of 16 or higher indicates risk of clinical depression. The reported internal consistency of the Greek version (Cronbach's alpha reliability) was 0.95 (Fountoulakis et al., 2001).

Procedure

The self-completed questionnaires were filled in by the mothers, in their homes, during one home visit by the researcher. The research protocol was approved by the scientific committee of the "Aghia Sophia" Children's Hospital. Written consent was given by all participants, after having been fully informed about the purpose of the study, confidentiality and their rights.

Results

Sample Demographic Characteristics

All the mothers in the study were of Greek nationality; the majority (88.7%) were married, and had two children (59%); 17.3% had a second child with ASD.

A high percentage of mothers (39.7%) were university graduates, and 4.9% had a higher degree, 18.1% had technological education, 24.2% were high school graduates, and 13.1% had completed secondary or primary school. Regarding the family income, 44.4% had an

income of over €30,000, 40.6% between €10,000 and €30,000, and 14.6% less than €10,000 per year. The majority of the mothers (58.9%) had a full-time job, 10.7% had a part-time job, and 23.2% were unemployed, 5.4% retired and 1.8% students.

Child Diagnosis and Clinical Characteristics

All the children had been diagnosed with ASD based on ICD10 criteria for Pervasive Developmental Disorders. The Autism Diagnostic Observation Schedule (Lord et al 2001, Papanikolaou et al 2009), and the Autism Diagnostic Interview Revised (LeCouteur et al 2003, Papanikolaou 2009) had also been administered. All the patients underwent a standard psychometric evaluation and were tested for fragile X and other chromosome abnormalities. The mean intelligence quotient (IQ) of the children was 74.09 ± 27.33 , range 30 - 111 (WISC III; Kaufman, 1976; Georgas, Paraskevopoulos, Bezevegis, & Giannitsa, 1997; Raven; Court & Raven, 1986; Mouzaki, Antoniou, Sideridis, & Simos, 2012).

When asked about the difficulties that their children faced (i.e., learning difficulties, attention problems, sleeping difficulties) the majority of the mothers reported learning disabilities (82.5%) and attention and hyperactivity problems (81.1%), while a smaller proportion (37.5%) reported that their children had difficulty in going to sleep. Over one third of the mothers (38.1%) reported that their child had received sedatives or other psychoactive drugs during the last 12 months.

Maternal Health Problems and Depressive Symptoms

Responding to questions about their own health, 46% of the mothers reported health problems. In an open-ended question, specific health problems listed were thyroid problems (17.07%), pains in the limbs (11.3%), gastrointestinal problems (9.2%), cardiological problems (5.2%), high levels of cholesterol (5.1%), myoskeletal problems (4.9%), hypertension (3.1%), and other health problems (17.3%) (e.g., arthritis or rheumatism, chronic respiratory problems, cancer), and internalizing problems (26.83%) (e.g., depression, anxiety). A high rate of mothers (69.1%) reported taking sedatives or other psychoactive drugs during the last 12 months. According to their scores on the

CES-D, 67.5% of the mothers presented symptoms of depression.

Family Cooperation and Parental Responsibility for the Upbringing of the Child

Examining the family environment, participants had the choice to describe their family by completing more than one characteristics, 70.36% characterized their family environment as positive (“collaborative” by 42.59%, “happy” by 16.67%, “calm” by 11.1%), and 44.45% as negative (“strong-uncooperative” by 11.12%, “confused” by 3.7%, “competitive” by 7.41%, “uncomfortable” by 3.7% and “chaotic” by 18.52%). Regarding agreement with the husband/partner on issues related to care and upbringing of their child with ASD, 35.9% of the mothers reported “moderate agreement”, 31.5% “slight agreement”, 18.5% “strong agreement”, 9.35% “very strong agreement”, and 4.75% of mothers reported “no agreement”. In addition, 64.71% of the mothers reported that they had the main responsibility for the care and upbringing of their child, while 35.29% reported that the mother and father shared the child’s upbringing. Estimating the total number of hours that the mother spent exclusively with the child, 62% reported up to 5 hours per day, 16.5% reported 5-7.5 hours per day, 12.0% reported 7.6-10 hours and 9.5% more than 10 hours.

Maternal Concerns for the Future

The concerns of the mothers about the future of their child are shown in Figure I. The key issue for most of the mothers was who will be responsible for the support (61.82%) and care of the child (58.18%) when they are no longer able to fulfill their role. Maternal concern about the challenges that their child will face during adolescence was also high (58.18%).

Maternal social support

The sources of support that the mothers reported receiving in the upbringing of their child are presented in Table 1. It appears that the main sources of support is the spouse (always 35.8%), but the mothers reported only a low level of support by friends/colleagues (not at all 66%).

Needs for information and support

Table 2 shows the responses of the mothers to questions about their perceived needs. Regarding the information needs, mothers appeared to be in need of information about the services available for the later developmental stages (“always”

35.7%) and how children grow and develop (“very often” 37.0%).

Examining their needs for support, mothers stated that they need to talk about problems with a member of their family (“moderately” 38.9%) and to have more time to talk with their child’s teacher or therapist (“moderately” 30.4).

Financial needs and burdens

Table 3 shows that the majority of parents did not need more help to cover therapy expenses, getting a job, paying for a babysitter and paying for toys, although one third of the mothers (33.9%) reported that sometimes they need more help for covering the monthly expenses (such as food, housing, medical care, clothing or transportation). Most of the mothers reported that having a child with ASD burdens the family’s finances (very much-extremely 61.8%).

Examining in detail the financial burden of families with a child with ASD, 15.1% of families spend €200 - €400 per month for the

child’s treatment, 13.2% €401- €800, 41.6% €801 -€1,200, 17% spend €1,201 -€2,000, and 13.2% spend over €2,001. As shown in Table 4, the majorities of the families (94.4%) has insurance coverage and receive welfare benefit (55.8%), but the total financial aid does not exceed €500 per month (69.1%).

A high percentage of mothers (44%) reported that the family was paying out-of-the-pocket an amount ranging from €401 to €1,000 per month, and 26% up to €400, 12% from €1,001 to €1,900, 4% over €1,901, and only 14% reported no additional expenditure.

Regarding changes in employment because of the demands of having a child with ASD, 36.4% of the participants reported that a family member quit working in order to care their child. Conversely, 50.9% stated that a member of their family had to get a job or work extra hours in order to cover the expenses of the child’s therapy.

Figure 1. Maternal Concerns for the Future of their Child with ASD (n=61).

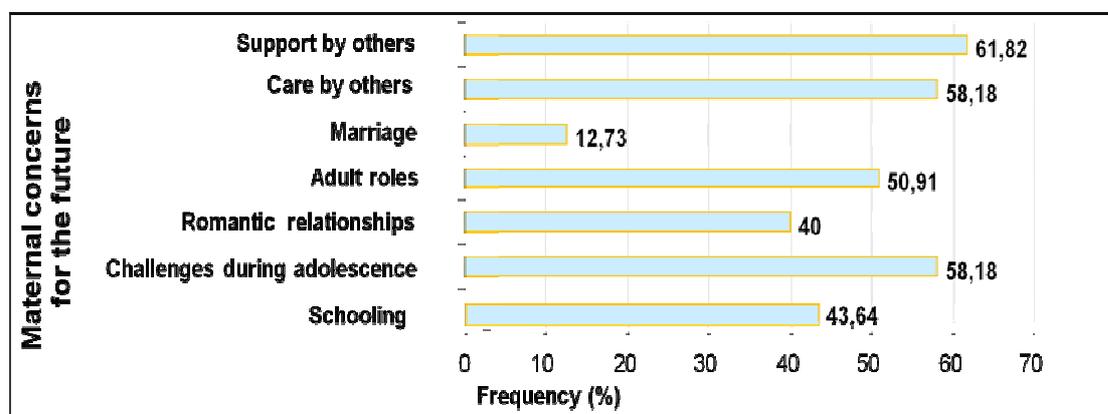


Table 1. Maternal Sources of Social Support in the Upbringing of their Child with ASD (n=61)

Sources of social support	Not at all N (%)	Sometimes N (%)	Often N (%)	Very Often N (%)	Always N (%)
Partner/Spouse	8 (15.1)	14 (26.4)	4 (7.5)	8 (15.1)	19 (35.8)
Grandparents	14 (26.4)	16 (30.2)	11 (20.8)	6 (11.3)	6 (11.3)
Friends/Colleagues	35 (66.0)	10 (18.9)	4 (7.5)	3 (5.7)	1 (1.9)
Professionals	4 (7.8)	16 (31.4)	12 (23.5)	10 (17.6)	10 (19.6)
Public services	8 (15.4)	26 (50.0)	11 (21.2)	6 (11.5)	1 (1.9)

Table 2. Needs of mothers of children with ASD for information and support (n=61)

Needs for information	Not at all N (%)	Sometimes N (%)	Often N (%)	Very Often N (%)	Always N (%)
About my child's condition or disability	6 (10.9)	15 (27.3)	15 (27.3)	8 (14.5)	11 (20.0)
How to handle my child's behavior	0 (0.00)	20 (35.7)	14 (25.0)	9 (16.1)	13 (23.2)
How to teach/ to play or talk to my child	7 (12.7)	16 (29.1)	14 (25.5)	8 (14.5)	10 (18.2)
About the services that are presently available for my child	9 (16.7)	7 (13.0)	17 (31.5)	9 (16.7)	12 (22.2)
About the services that my child might receive in the future	2 (3.6)	9 (16.1)	14 (25.0)	11 (19.6)	20 (35.7)
How children grow and develop	2 (3.7)	7 (13.0)	9 (16.7)	20 (37.0)	16 (29.6)
Needs for support	Not at all N (%)	Slightly N (%)	Moderately N (%)	Very N (%)	Extremely N (%)
To have someone in their family that they can talk more about problems	8 (14.8)	15 (27.8)	21 (38.9)	4 (7.4)	6 (11.1)
To have more friends that they can talk to	15 (26.8)	23 (41.1)	8 (14.3)	7 (12.5)	3 (5.4)
To have more opportunities to meet and talk with other parents/to read material about other parents who have a similar child	7 (13.0)	22 (40.7)	14 (25.9)	7 (13.0)	4 (7.4)
To have more time to talk with their child's teacher or therapist	7 (12.5)	13 (23.2)	17 (30.4)	12 (21.4)	7 (12.5)
To have more time for myself	9 (18.0)	21 (42.0)	14 (28.0)	2 (4.0)	4 (8.0)

Table 3. Financial needs of mothers of children with ASD (n=61)

Need more help	Not at all N (%)	Sometimes N (%)	Often N (%)	Very Often N (%)	Always N (%)
In paying for expenses, such as food, housing, medical care clothing or transportation	12 (21.4)	19 (33.9)	11 (19.6)	7 (12.5)	7 (12.5)
In getting special equipment for their child's needs	26 (46.4)	15 (26.8)	9 (16.1)	2 (3.6)	4 (7.1)
In paying for therapy, day care, or other services their child needs	100 (00.0)	0 (00,0)	0 (00,0)	0 (00.0)	0 (00.0)
In getting a job	34 (61.8)	7 (12.7)	6 (10.9)	5 (9.1)	3 (5.5)
In paying for babysitter or respite care	27(50.09)	12 (22.6)	8 (15.1)	2 (3.8)	4 (7.5)
In paying for toys that their child needs	25 (47.2)	17 (32.1)	7 (13.2)	2 (3.8)	2 (3.8)
With the financial burden	Not at all N (%)	Slightly N (%)	Moderately N (%)	Very much N (%)	Extremely N (%)
	7 (12.7)	5 (9.1)	9 (16.4)	17 (30.9)	17 (30.9)

Table 4. Coverage of cost of therapeutic interventions for children with ASD (n=61)

		N	(%)
Insurance coverage	Yes	51	(94.4)
	No	3	(5.56)
Cost (in euros) covered by insurance	0-250	17	(40.5)
	251-500	12	(28.6)
	501-750	6	(14.3)
	751-1,000	4	(9.5)
	1,251-1,500	2	(4.8)
	≥1,501	1	(2.4)
Welfare benefit	Yes	24	(55.8)
	No	19	(44.2)

Discussion

This study set out to explore the burdens and needs of families with children with ASD in a sample of Greek mothers. Having a child with ASD was perceived to be a burden on the family's finances in this population. The mothers also appeared have insufficient information about future issues related to the child with ASD, such as the services available for later developmental stages, and what to expect in the next developmental period of the child. They expressed the need to talk more about the child's condition with other family members, and their child's teacher or therapist. In accordance with other studies, the mothers reported high rates of mental and physical health problems (particularly thyroid dysfunction, pains in the limbs and gastrointestinal problems) (Allik, Larsson & Smedje, 2006; Bilgin & Kucuk, 2010; Dale et al., 2006; Hastings et al., 2005; Weiss 2002), and high levels of depressive symptoms (67,5%) while a low level was found in a sample of Greek community from the same area 27,1% reported a significant number of dysphoric or depressive symptoms (Madianos, Goumas, Stefanis, 1992).

Some studies have linked the mental health problems of mothers with the dependency and the increased needs of their children with ASD (Schieve et al., 2007; Seltzer et al., 2004; Wolf et al., 1999). Only one third of the mothers in our study shared the responsibility of child care and upbringing with the father, and about 40% of them spent 5-10 hours per day exclusively with their child. These findings document a heavy burden on the maternal role incurred by the care and upbringing of their child with ASD.

Many mothers reported that the level of agreement between the mothers and fathers in issues related to

their child upbringing was low, similar to the parents in another study, who reported lower family cohesion and family adaptability compared with parents in a control group (Higgins et al., 2005). In spite of this, the majority of mothers in our study characterized the family environment as positive (mainly collaborative). This discrepancy may be due to the strong ties in the extended family that are still observed in Greek communities.

Regarding the main maternal concerns about the future of their children, the most frequently cited issue was support and the care of the child when they themselves are no longer able to provide it. This may be related to their reports that the social support from friends and colleagues is extremely low, and therefore they may feel isolated. Concerns about the challenges that their child would face during adolescence were also high (58.18%). Their need for more information about the next developmental stages and services for older children may derive from the difficulty of health professionals to predict the exact prognosis of the child with ASD. This uncertainty causes parents more stress, as it makes their own responsibilities a greater and planning for their child's uncertain future a huge challenge (Weiss, 2002). It is not uncommon for these parents to feel pessimistic when thinking about the long-term prospects for their children, believing that their children will not be able to live without support (Kotsopoulos, 2014).

Examining the support that the mothers receive in bringing up their child, the spouses were named as the main source of support, while the social support from friends and colleagues, grandparents, professionals and the public services was reported as low. This lack of family and social support was confirmed by the need that the mothers expressed to

talk more with a family member and the teacher or therapist of their child. The social isolation of these families may cause them to seek more support from their extended family or professionals who interact with their child, but it may drive them to persevere alone. Previous evidence also suggests that families raising children with ASD are characterized by low social support and adapt avoidant coping strategies to manage their problems and handle their stress (Cappe et al., 2011).

Regarding the financial burden in families, 41.6% of families spend €801- €1,200 for their child's treatment. The majority of the families have insurance coverage and welfare benefit not exceeding €500 per month. This means that they have monthly out-of-their-pocket payments usually ranging from €401 to €1,000. It is not surprising, therefore, that half of the participants reported that a family member had to get a job or to work extra hours in order to cover therapy expenses. These findings corroborate the data from previous studies, suggesting that families raising children with ASD face a reduction of the family income, high costs and financial difficulties because of the increased health and educational needs of their children (Järbrink et al., 2003; Montes et al., 2008;).

The finding that 36.4% of families had a member who had to quit their job in order to care for the child is in agreement with a survey showing that 39% of parents with a child with ASD had child care problems that affected their employment decisions (quit a job, not taken a job or greatly changed their job) (Montes & Halterman, 2011).

This study had a number of limitations that should be taken into consideration. There was insufficient representation of families of lower socio-economic and educational background, thus reducing the generalizability of the results. A second limitation was that maternal emotional state was only measured with a self-report questionnaire. Nevertheless CES-D is a highly sensitive tool, however, and has been used to detect depression in the general population and has been used in Greek populations (Fountoulakis, Iacovides, Kleanthous, Samolis, Kaprinis, Sitzoglou, & Bech, 2001; Madianos, Goumas, Stefanis 1992). Finally, this study examined the impact of ASD only as perceived by the mothers, overlooking the role of fathers. The mothers were selected as being the crucial primary caregivers, who often make the major contribution to the parenting of their children. Further studies are required to explore the perceived social support and needs of fathers in the Greek population and to identify possible differences in perceptions and concerns between mothers and fathers of children with ASD.

Despite these limitations, this study is the first to our knowledge that examines the financial burdens

and needs; it highlights the impact of raising a child with ASD in Greek families on the psychological well-being, career decisions and social life of the mothers and their enormous needs for support, and also raises the issue of agreement between parents, and family cooperation.

Given that currently the capacity to increase public and private expenditure on the health and education of children with ASD in Greece is limited, it is essential for the informal support networks to be strengthened. The wider community needs to become more aware of ASD, in order to alleviate the labelling and social isolation of these families. It is important for those who hold "key positions" in the local community and schools to become better informed on issues related to ASD, and in general the prevention and promotion of psychosocial health, not only for the children, but for the whole family. Finally, there is an urgent need for the establishment of an effective well-organized health network system and education services, which will be able to meet the needs of children with ASD throughout their life.

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